SATISFACTION WITH END-OF-LIFE CARE AND COMMUNICATION: RELATIONSHIPS BETWEEN FAMILY/RESIDENTS AND STAFF PERSPECTIVES

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ABSTRACT

Families are increasingly relying on nursing homes as the place where the resident receives end-of-life (EOL) care. Improving the quality of the EOL experience in nursing homes has become a national focus. Past studies have examined EOL care from either the family/resident or staff perspective, but few have integrated the two perspectives. Using Unruh and Wan's (2004) expanded structure, process, and outcomes framework, the study proposes to explore the relationship of satisfaction with EOL care and communication between families of deceased residents and nursing homes staff.

The study is a descriptive, secondary data analysis from a larger study examining EOL care in nursing homes. Participants were families of deceased residents (*N*=1,282) and nursing home direct care staff *(N*=2,962). Family members of deceased residents provided information on *satisfaction with communication* (1-item), *satisfaction with care* (6-items), and *care focused on the individual* (6-items). Staff completed surveys on *satisfaction with communication* (3-items), *satisfaction with EOL care* (8-items), and *attitude toward death* (3-items). Data were aggregated to the facility level (*N*= 85) to integrate staff and family data for analysis using Pearson correlations (*r*).

Family satisfaction with care was highly correlated with care focused on the individual resident (*r*=.78). Staff satisfaction with communication was moderately correlated with staff satisfaction with EOL care (*r*=.39). Staff satisfaction with communication was moderately correlated with family satisfaction with communication (*r*=.31), family satisfaction with care (*r*=.32) and care focused on the individual (*r*=.27).

Individualized care focused on the resident is necessary for increasing family satisfaction. Better communication between staff and families can enhance the quality and satisfaction with EOL care. Future development of EOL care interventions should include a comprehensive evaluation that integrates both perspectives from staff and families of residents.

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INTRODUCTION

Families are increasingly relying on nursing homes as the place where the resident receives end-of-life (EOL) care; past studies have reported that 35 of every 100 residents will die in the nursing home (Jackson et al., 2012). However, many nursing homes are currently lacking in quality EOL care. Many nursing homes offer little staff education regarding EOL care, poor transitions to palliative care, and focus primarily on task-based care. In light of this knowledge improving the quality of the EOL experience in nursing homes has become a national focus.

Past studies have examined EOL care from either the family or resident perspective or from the staff perspective, but few have integrated the two perspectives. The purpose of this study is to investigate staff and family member perspectives regarding end-of-life care and communication in nursing homes by examining aggregated data collected from Midwestern nursing homes. If strong correlations are found it would allow staff member data to serve as a proxy for family member data, reducing the need to collect data from family members that is costly and resource intensive in future studies. Strong correlations would also provide direction for interventions aimed at improving EOL care in nursing homes.

The following four research questions will be explored: (1) Is there a relationship between family members' perceptions of resident-focused care, their satisfaction with communication and their satisfaction with EOL care? (2) Is there a relationship between staff members' satisfaction with communication, satisfaction with EOL care, and attitude toward death? (3) Is there a relationship between family members' satisfaction with EOL care and staffs' perceptions of EOL care? (4) Is there a relationship between family members' satisfaction with communication and staffs' satisfaction with communication?

BACKGROUND

Families report higher satisfaction with EOL care when providers show concern and compassion, openly communicate about impending death, and communicate well with other staff members (Jackson at al., 2012, Thompson, Menec, Chochinov, & McClement, 2008). Satisfaction among the family members is related to the belief that the staff cares, that staff are present, and there is continuity of care (Jackson et al., 2012). Residents also

report individual, personalized care as another factor leading to increased satisfaction (Forbes-Thompson & Gessert, 2005). However, many family members feel that there is a lack of realistic communication, or "irrational optimism" from the staff regarding the resident's impending death, and some families report feeling misinformed about EOL care measures (Jackson et al., 2012). Decreased satisfaction also has been associated with care that focuses solely on physical needs and ignores the resident's psychosocial needs (Forbes-Thompson & Gessert, 2005).

Some of the problems reported by families may be due to a lack of clear palliative care policies and lack of EOL education among staff (Jackson et al., 2012). Studies have identified that staff feel it is difficult to balance the needs of the residents and the requirements of regulations that must be followed within the nursing home setting (Waldrop & Nyquist, 2011). Staff also report difficulty identifying patients that are terminally ill (Forbes, 2001), making it difficult to know when to initiate palliative care and EOL discussions with the resident and/or family members. This is compounded by the fact that most of the staff that provide direct care to residents are unlicensed personnel (Certified Nursing Assistants) who have not had the EOL training. Other barriers to EOL care include staff reports of feeling uncomfortable with residents who are dying and initiating discussions about death. Additionally high patient to staff ratios prevent staff from spending time that is necessary caring for the resident's psychosocial needs. Thus, interventions that can increase satisfaction with the EOL experience from both the family and the staff's perspectives need to be explored and tested.

THEORETICAL FRAMEWORK

Unruh and Wan's (2004) expanded structure, process and outcomes framework was used to design the larger study from which the data were collected. This study focuses on those aspects of the model related to the processes of care that staff provide (satisfaction with communication and EOL care, and attitude toward death) and the outcomes experienced by the resident and/or family (resident/family centered care and satisfaction with care and communication).

METHODS

DESIGN

This study used a secondary data analysis using a correlational design. Data collected as part of a larger study (Thompson, Gajewski, Bott, & Tilden, 2013) examining the quality of EOL care in nursing homes (N = 85) were used for this research.

SETTING AND SAMPLE

The original study selected 85 urban and rural nursing homes across Nebraska and Iowa. Data were collected from families of decreased residents (N=1,282) and direct care staff members (N=2,247). Residents were predominately white (98.6%) and female (67.7%), and most were over 85 years of age (64.2%). Similarly, family members were predominately white (98.9%) and female (70.9%). More of an age variation was seen among family members, but 56.5% were under the age of 65. Family and resident characteristics are outlined in Table 1.

Direct care staff members were defined as assistant directors of nursing (1.3%), shift supervisors (4.2%), Minimum Data Set (MDS) coordinators (2.6%), staff nurses (registered nurses [RNs] and licensed practical nurses [LPNs], 2.6%), certified nurse assistants (CNAs, 51.8%), and certified medication aides (CMAs, 17.0%). Staff members were predominately 25-44 (41.4%) and 45-64 (36.5%) years of age. Most were white (79.2%) and female (94.1%). Only 7.4% of staff members held a bachelor's degree. Many had been working at their current job for 1-5 years (35.8%), and some had been there less than 1 year (13.2%). Table 2 outlines the staff member characteristics.

MEASURES

Teno, Casey, Welch, & Edgman-Levitan (2001) developed the scales and items used to measure family member perceptions of care. *Care focused on the individual* is a six-item scale that asks family members if the resident's individual needs were met on a scale that ranged from zero to three (never =0, sometimes = 1, usually = 2, and always = 3). Response options were recoded so never, sometimes and usually were scored as no (0) and always was recoded to yes (1). The coefficient alpha for this scale was 0.87. The *satisfaction with care* scale is a six-item scale ranking satisfaction on a scale that ranged from zero to -10. The scale coefficient alpha was 0.95. Scores were summed across the items for each of the scales respectively and higher score represented better care focused on the individual (*range* = 0 to 6; *midpoint* = 3) and greater satisfaction with care (*range* = 0 to 60; *midpoint* = 30) A single item (i.e., How well did the staff communicate with the resident and the family about the illness and the likely outcomes of care?), taken from the *satisfaction with care* scale, was used to determine family satisfaction with communication. Higher scores represent better communication from the staff (*range* = 0 to 10; *midpoint* = 5).

Staff members' *satisfaction with communication* was measured using a three-item scale ranking satisfaction from one to six (very dissatisfied = 1, dissatisfied=2, slightly dissatisfied=3, slightly satisfied=4, satisfied=5, or very satisfied=6) (Shortell, Rousseau, Gillies, Devers, & Simons, 1991, Scott-Cawiezell et al., 2004**)**. Scores were averaged across the three items for a *range* of 1 to 6 with a *midpoint* of 3.5; the reliability of the measure was α =0 .87. *Satisfaction with care* (8 items) and *attitudes toward dying* (3 items) were measured using response options ranging from one to four (never = 1, sometimes = 2, often = 3, and always = 4) (Forbes-Thompson, Gajewski, Scott-Cawiezell, & Dunton, 2006). Scores were created by averaging across the number of items so the *range* was one to four with a *midpoint* of 2.5. Coefficient alphas for the two scales were 0.63 and 0.81, respectively. Higher scores represent greater satisfaction with care and communication and more positive attitudes towards residents' deaths.

PROCEDURES

Staff at Midwestern long-term care facilities completed surveys regarding education, communication, teamwork, leadership, and palliative care in group settings. Family members were surveyed by phone approximately six weeks after the resident's death. For this study, de-identified data from nursing home staff and family members regarding their perceptions of care were aggregated to the facility level in order to correlate data across the nursing homes. A Midwestern academic medical center Institutional Review Board reviewed the study and made a determination of non-human subject research because all data were de-identified for this study.

DATA ANALYSIS

Scale scores were aggregated to the facility level for each nursing home (*N*=85). IBM Statistics SPSS Version 20.0 was used first to examine frequencies and descriptives, and to calculate Pearson correlations (*r*) among the variables of interest. The *p* value was set at 0.05.

RESULTS

DESCRIPTIVES

Overall both family members and staff members reported scores above the midpoint on all scales and measures. For family members this represented higher satisfaction with care focused on individual, satisfaction with EOL care, and satisfaction with communication. Staff members also reported higher satisfaction with EOL care and communication as well as a more positive attitude toward death. Mean scores and standard deviations for each of the scales can be found in Table 3.

CORRELATIONS

Family Members. Family member variables were correlated to determine if there is a relationship between satisfaction with communication, satisfaction with care, and care focused on the individual. Strong, positive correlations (r = 0.72 to 0.89) were found among all three variables (See Table 4).

Staff Members. Correlations within staff member variables (i.e., communication, satisfaction with EOL care, and attitudes toward dying) were examined. A moderate correlation (r = 0.39) was found between satisfaction with EOL care and satisfaction with

communication; a small positive correlation (r=0.24) was found between satisfaction with EOL care and attitudes toward dying; no correlation was found between attitudes toward dying and satisfaction with communication (see Table4).

Staff Members with Family Members. Moderate correlations were found between family satisfaction with communication and staff satisfaction with communication (r = .31), and family satisfaction with care and staff satisfaction with communication (r = .32). Small correlations were found between family perceptions of care focused on the individual and staff satisfaction with communication (r = 0.27), and family perceptions of care focused on the individual and staff satisfaction with EOL care (r =0.24). No significant correlations were found among the other variables (see Table 5).

DISCUSSION

Findings from this study suggest that families that are highly satisfied with communication also would be more likely to be satisfied with overall care and care that is focused on the individual needs of the resident. Although there were small to moderate correlations between staff satisfaction with communication and family satisfaction with communication, the associations were not as strong as expected. This may be representative of a possible disconnect between families and staff regarding what is important to communicate and the quality of care that is being provided. One possibility is that staff may feel less satisfied with the care they are able to provide but this may not affect the quality of care from the family's perspective. This may be due to conflicts between resident needs and the time constraints to attend to those needs that is created by lack of staffing or other regulations (Waldrop & Nyquist, 2011) that staff perceive as

impediments to care. **I**n comparison to the other scales in the study, staff reported satisfaction with EOL care at the about the midpoint of the scale, while satisfaction with communication was much higher. Although it does not indicate that staff were dissatisfied with the care, they were not highly satisfied with the EOL care they provided.

Another factor impacting the quality of end-of-life care is the very low percentage of direct care staff with bachelor's degrees. From this one can surmise that the majority of direct care providers have little formal knowledge or training in EOL care principles and lack the necessary competencies needed to initiate conversations about EOL care desires and wishes, appropriately assess the resident's needs, and provide the care needed to meet those needs. With this in mind it is important to design interventions focusing on on-the-job training to increase staff comfort in addressing EOL care. High turnover in nursing homes also require the need to train staff during orientation, as well as provide follow-up training at regular intervals.

Another interesting finding was that staff's *attitude toward dying* scores only had low correlations with staff's satisfaction with communication and EOL care, and essentially no correlation with family satisfaction with EOL care and communication and care focused on the individual. On average staff's scores on the *attitude toward dying* scale were well above the midpoint of the scale indicating that staff had a positive attitude toward dying in the nursing facilities that participated in this study. One would anticipate that staff who reported that they "did not feel awkward and were comfortable when spending time with dying residents" would also report that they were more satisfied with EOL care and communication. However, one's personal comfort with death and dying does not

necessarily translate to higher satisfaction with the communication process or the quality of the EOL care that is provided in the nursing home. In future studies it may be useful to explore this further to see if there are other reasons that this relationship did not surface.

Lastly, by aggregating variables to the facility level there may be a loss in variability across response options because staff responses and family member responses are averaged to represent how all staff and all families perceive each variable of interest within the facility. Depending upon how representative the family members and staff members were of the nursing home and the limited variability through aggregation, the true relationships that may be present (either positive or negative) may be masked. Further research is necessary to validate the findings of this study as well as comparing other variable such as across states or between urban and rural nursing homes.

CONCLUSIONS

Strong correlations within all family member variables were found. Correlations within staff member variables were not as consistent and were not as highly correlated. Variables that were moderately positively correlated between staff and family members were satisfaction with communication and satisfaction with care. Family members positive perceptions with care focused on the individual resident had some positive correlation with staff satisfaction with EOL care and satisfaction with communication.

IMPLICATIONS

Findings from this study support better quality of care being achieved by integrating both perspectives from family members and staff members in designing interventions to improve quality EOL care in nursing homes. Findings do support that staff satisfaction with

communication is important to family member's perceptions of quality of care. While correlations may not have been strong enough to support using staff satisfaction as a proxy for family satisfaction, this study did show the impact of communication on EOL care. In the future EOL care interventions focusing on improving communication among staff and families need to be developed and tested to increase the quality of EOL care that residents receive in nursing homes.

LIMITATIONS

The findings from this study may not be able to be generalized to all nursing homes. Although nursing home residents are predominantly female, there may be other nursing homes that have a higher proportion of other races and ethnicities, which would have very different response based on cultural beliefs and expectations. Additionally, these data were collected from only two midwestern states. In order for these findings to be applied to broader populations this study must be replicated in multiple settings with a wider range of participants.

TABLE 1 FAMILY MEMBER AND RESIDENT CHARACTERISTICS (*N*=1,282)

Characteristic	Category	Family (%)	Resident (%)
Age	< 65 years	56.5	1.3
	65-74 years	27.0	6.4
	75-84 years	12.4	28.2
	> 85 years	4.1	64.2
Gender	Female	70.9	67.7
Race	Caucasian	98.9	98.6
Employed	Yes	54.8	N/A
Religion	Protestant	74.2	74.5
	Catholic	20.1	18.7

TABLE 2 STAFF MEMBER CHARACTERISTICS (*N*=2,247)

	Staff	
Characteristic	**Category**	***%***
Age	< 24 years	18.6
	25-44 years	41.4
	45-64 years	36.5
	≥ 65 years	3.6
Gender	Female	94.1
Education	≤ High School or GED	59.6
	Associates Degree	33.1
	Bachelors or Higher	7.4
Race	Caucasian	79.2
Years at Current Job	< 1 year	13.2
	1-5 years	35.8
	6-10 years	17.8
	11-15 years	11.2
	16-20 years	8.5
	≥ 20 years	13.4

TABLE 3 MEASURE DESCRIPTIVES FROM FAMILY AND STAFF MEMBERS (*N*=85)

	Family Members	**Staff Members**
	M(SD) ***Midpoint***	***M(SD)*** ***Midpoint***
Care Focused on the Individual	4.16 (0.64) 3	N/A
Satisfaction with EOL Care	52.44 (3.47) 30	2.57 (0.18) 2.5
Satisfaction with Communication	8.50 (0.64) 5	4.51 (0.33) 3.5
Attitude Toward Death	N/A	3.64 (0.13) 2.5

TABLE 4 CORRELATIONS BETWEEN SATISFACTION VARIABLES WITHIN FAMILY MEMBERS AND STAFF MEMBERS.

	A. (*r*)	**B. (*r*)**	**C. (*r*)**	**D. (*r*)**	**E. (*r*)**	**F. (*r*)**
	Family members					
A. Satisfaction with Communication	-					
B. Satisfaction with Care	0.89**	-				
C. Care Focused on the Individual	0.72**	0.78**	-			
				Staff members		
D. Satisfaction with Communication				-		
E. Satisfaction with EOL Care				0.39**	-	
F. Attitude Toward Dying				0.19	0.24*	-

*$p \leq .05$
**$p \leq .01$

TABLE 5 CORRELATIONS AMONG SATISFACTION VARIABLES BETWEEN STAFF MEMBERS AND FAMILY MEMBERS

		Family Members		
		Satisfaction with Communication (***r***)	Satisfaction with Care (***r***)	Care Focused on the Individual (***r***)
Staff Members	Satisfaction with Communication	0.31**	0.315**	0.27*
	Satisfaction with EOL Care	0.13	0.16	0.24*
	Attitude Toward Dying	0.01	0.04	0.00

*$p \leq .05$
**$p \leq .01$

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